

Resources for Families and Caregivers

May 2022

Local Resources







- Vermont Mental Health and Grief Support Resources
 - o Grief support groups and resources listed by county in Vermont
- Vermont Ethics Network
 - A Vermont organization bringing awareness to medical ethics and aid in advanced care planning, palliative care and end of life care.
- Vermont Home Health Family and Support Services
 - Information about family support services offered in Vermont through the University of Vermont Health Network Home Health and Hospice.
- Vermont Department of Mental Health
 - Vermont Department of Mental Health- resources for mental health services and support for children, youth, and family
- Vermont Family Network
 - A Vermont organization that organizes support, education, and activities to empower Vermont families with children who have disabilities or special health needs.
- UVMMC Patient, Family and Caregiver Support Groups
 - Additional VT grief and support groups
- Vermont Assistive Technology Program
 - Information about assistive technology, borrowing equipment, demonstrations, and accessible solutions for disability related needs

National resources & Useful Websites

- International Children's Palliative Care Network (ICPCN)
 - Platform that provides a "one stop shop" for information and resources related to children's palliative care
- Pediatric Palliative Care Coalition (campaign-archive.com)
 - Join the mailing list to be included in Newsletters, virtual events, webinars or online messaging groups
- Courageous Parents Network
 - A platform that empowers families and assists them in advocacy, planning, understanding of interventions, coping and bereavement over the course of the child's diagnosis.
- Together for Short Lives
 - Family support resources and information about diagnosis, transition to adult services, end of life care, and bereavement support



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Camps, Programs & Support Groups

Camp Sunshine

 Free, week-long camp sessions year-round for children living with life threatening illness and their families, including accommodations and medical care in Casco Maine.

Double H Ranch

 Provides specialized programs and year-round support for children and their families dealing with life-threatening illnesses. All programs are FREE of charge and capture the magic of the Adirondacks in Lake Luzerne, NY.

Hole in the Wall Gang Camp

 With unobtrusive expert medical care, it was Paul's dream that Camp would provide seriously ill children with a fun-filled experience defined by compassion, laughter, and acceptance, in New Haven, CT.

Beads of Courage

 Encouraging beading for kids with life altering conditions and their siblings to encourage communication, expression, resilience and strength and represent their journey

Make a Wish Foundation

o Providing wishes for children with life altering or critical illnesses

CaringBridge

 Free, secure, site on which you can share updates about your loved one.

Take Them a Meal

 simplifying meal coordination so friends, family, neighbors, and coworkers can show they care

Support Groups and Resources through Vermont Family Network

 Helpline, SibShops, Parent Matches, Funding for Families, Support Groups

• Perinatal Palliative Care

 Clearinghouse of information and resources about perinatal palliative and hospice care.



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Bereavement Support

- GrieveWell
 - Nonprofit organization that provides resources and support to grieving adults
- Bereaved Parents USA
 - A safe space where grieving families can connect, share stories and support each other in hoping and healing
- The Compassionate Friends
 - A support group for families and individuals to meet with people who have experienced a life-altering event and loss. It's a way for those to find purpose and meaning with others who have had similar experiences.
- Now I Lay Me Down to Sleep
 - Remembrance photography by a network of professional photographers
- Central Vermont Health & Hospice Grief and Loss Support Groups
 - Grief and loss support groups held weekly over zoom
- Camp Knock Knock
 - "A weekend bereavement camp for families with children who have experienced the death of a loved one." In North Hero, VT.
- The Dougy Center
 - Online resources with tip sheets, activities, podcasts, and personalized toolkits.
- The Children's Room
 - Creating safe, supportive communities so that no child, teen, or family has to grieve alone.

Apps

- Pediatric Palliative Care Coalition
 - A free app designed for family and caregivers to help manage daily medical details for children with complex medical conditions
- Calm Mindfulness
 - This app guides people through meditation and breathing exercises to help with self-care and is easily accessible for any smartphone user.